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## **CULTURAL INFLUENCES ON NAVAJO MOTHERS WITH DISABLED CHILDREN**

Jennie R. Joe

It has been noted by social scientists that there are common patterns of parental response to the introduction of a severely disabled child into a family. Some initial responses are shock, bewilderment, confusion and disbelief (Ross, 1964; Schlesinger, 1972). These initial responses, while brief, often set the stage for other, more permanent, perceptions. Concomitantly, along with the first reactions are a series of questions asked by the parents of the disabled child.

One such question invariably asks, "why"? In answer, some parents -- particularly mothers -- will blame themselves for the child's disability; a process of self-blame which may take many forms. For some mothers, their search for answers may lead them to recount certain events in their lives, seeking situations which could possibly demand, or warrant, some form of reprisal. Needless to say, these perceptions are bounded by sociocultural experiences and orientation which may be more common in some societies than others. For instance, a Navajo mother -- shocked at seeing her newborn child with cleft lip and palate -- may not question the physician's explanation of how the defect occurred, but her lingering question of "why" may not be satisfied until she has reviewed her own prenatal history to account for any breach of tribal prenatal taboos and/or has consulted a Navajo diagnostician.

Failure on the part of medical anthropologists and other social scientists to give equal importance to the question

of "why" and/or "how" may create unnecessary misunderstandings and faulty analyses. Granted, this suggestion may appear easier said than done, especially when there are many forms of illnesses with unknown etiologies and with questionable methods of treatment. Unfortunately for the disabled, many chronic disabling conditions fall into these unknown categories. Thus, from the standpoint of disabled children and/or their families, the revelation of unknown entities often increases an existing stressful situation. Under these circumstances, it is not unusual for the disabled and their families to sense the powerlessness of medical science and perhaps view the situation as totally hopeless.

In cross-cultural comparison, these chains of events for an Anglo family, familiar with the shortcomings of their healing system, may be less devastating than for a family from a non-Western culture. In most instances, the situation is complicated even more for the bi-cultural person, such as a modern-day Navajo, whose tribal language and conceptual experience do not provide for adequate translation or full comprehension of the situation.

In addition to coping with some of the initial shocks and frustrations of having a disabled child, the impact on the family is just beginning — one common impact, noted by Farber (1959), is the disruption of parental role. Farber has observed that in Anglo society, which is a child-centered society, the disruption often interferes with family goals and extends the parenting role. In other words, the complex and long-term needs of the severely disabled child demand that the role of parent-to-dependent child be prolonged, sometimes indefinitely. The impact on the parenting role is also complicated by the sudden introduction of professionals and experts who direct the parents in the care and rearing of the disabled child, additional demands which become complicated and time-consuming.

Again in cross-cultural comparison, one might ask how this same situation is handled in adult-centered societies, such as the Navajo. Observers of Navajo culture have frequently referred to the Navajos as being adult-centered in the rearing of their children (Allen, 1963; Kluckhohn and Leighton, 1948; Leighton and Leighton, 1944; Leighton and

Kluckhohn, 1947). In Navajo society, children are treated as adults much sooner than in Anglo society. Evvard and Mitchell (1966) observed that modern-day Navajo children were still considered as adjunct to the adult Navajo world; for example, a Navajo girl of age six is expected to know how to prepare dough for bread and to assist in caring for her younger siblings. Similarly, Navajo boys of the same age are expected to herd sheep independently for a few hours a day and to assist in the care of livestock. In contrast, Anglo children of comparable age do not usually have the same expectations in fulfilling adult-like roles.

With the persistence of some Navajo form of child-rearing, one would assume that when a severely disabled child becomes part of a Navajo family, the impact would be greater because of the early demands on Navajo children to become independent and to assume adult-roles. This general hypothesis was explored at some length in a study of disability in Navajo society on the reservation, spanning 15 months between 1976 and 1978.<sup>1</sup>

After an initial reservation-wide collection of baseline information on the disabled, a small sample of 30 disabled Navajo children and their families were selected for a more intensive study. The children were of school age between six and ten. Fifteen of the children were visibly handicapped, their form of disability resulting from a childhood infectious disease, meningitis (an inflammation of brain coverings, due primarily to bacterial infection), the residual effects of which are similar to neurological defects in cerebral palsy. The remainder of the children were not noticeably handicapped, but had been identified by teachers and school psychologists as having learning disabilities.

The selection of children was based on a number of criteria, including the presence of visible and invisible forms of disabilities. One other criterion was that the children be of school age -- an age group normally expected to require less parental supervision. The 30 children came from different parts of the reservation; were enrolled or participating in some special education program or resident in programs for the handicapped. The overall age for the 19 boys and 11 girls was 8.3. Approximately 30% of

the children were first-born, with about 10% an only child. The age at diagnosis varied, but the majority with learning disabilities were not identified until after school entrance. Most of the children disabled by meningitis, on the other hand, were diagnosed between the ages of two and four. Both groups, in general, had uneventful prenatal and birth histories; most were also born in the hospital.

The majority of the parents in this study were in the early and mid-thirties, with the average age of the mothers, 33.3. Seventeen of the 30 children came from intact homes where both parents were present. Thirty-six percent of the children came from homes with single parents, usually mothers. The average number of children among the 30 families was 3.3.

Educationally, the average age of schooling for the entire group of 30 mothers was 6.5; the 19 boys' fathers averaged 6.6 years; in all, four of the mothers had no formal schooling. Thus, in general, the majority of the mothers had less than an eighth grade education and, as a result, most of them were quite traditional and less acculturated than expected.

Economically, as is common on many reservations, these Indian family incomes were below the national average. During 1977, the average family income was \$10,296, but the income pattern fluctuated, however, depending on availability of seasonal work. During peaks of unemployment, about half of the families were on public assistances, which represents an increase of about 30% from the normal 20% whose sole income is from welfare. It is understandable then, that economic hardship was one of the most frequent problems encountered and was a significant factor influencing the family's decision to institutionalize and/or have their disabled child remain institutionalized. For some of the families, the economic hardships were further complicated by other family crises, as is reflected in the following case of Josie.<sup>2</sup>

Josie was admitted at the age of nine into one of the private residential programs for handicapped Navajo children on the reservation. Prior to this, Josie was kept at home, cared for by her mother and, sometimes, her father.

Residential staff noted that when Josie was first admitted, she was in diapers and would only take nourishment from a baby bottle. Later, during a series of interviews with Josie's parents, they said they did not know how to care for her, except as a baby, since she was unable to do things for herself; she had not learned to walk, talk or groom herself. Josie's father said he, his wife, and relatives were too proud to ask for help or seek advice on how to care for or manage Josie. It was not until Josie's mother was accidentally injured that the family considered placing the child in a residential program.

Since the onset of the disability, Josie's parents had been advised often by physicians and nurses that they should consider placing the child in a state institution, but the facilities were far from the reservation, so they chose to wait. In the meantime, the parents avoided taking the child to the doctors unless she was sick because they wanted to avoid the discussion of institutional placement. Feeling that physicians were of little help, Josie's parents sought help from Navajo medicine men. According to Josie's mother, they went to at least two diagnosticians who outlined several different ceremonies which would be helpful. When the family was financially able to afford it, they had some of the ceremonies performed for Josie who, according to the mother, generally improved after a ceremony. As time went on, however, Josie became less cooperative and the remaining recommended ceremonies became too expensive. Other interruptions also caused the family to discontinue the ceremonies for the child. The mother's accident and the grandmother's illness were mentioned several times during interviews.

After the mother's accident, Josie's father and grandmother attempted to care for both of them, with the help of Josie's aunt, which sufficed for a while. When a community health worker came to the house, she recommended that the parents visit one of the residential programs to see if Josie could be enrolled. After Josie was placed in the program, the family was delighted with her progress. She was weaned from the bottle and developed some muscular control with physical therapy. On several occasions, Josie's mother publicly expressed her appreciation of the program staff for helping her daughter, saying that she

would not have known about the services nor the various approaches used to help disabled children.

In another example, the family hardship is more vivid. James came into one of the residential programs for trial admission -- a period of thirty days. During this trial period, the staff evaluates the child and determines if the child can benefit from the program. During the initial admission conference, James was wheeled into the conference room by his grandparents. Although James was older, he resembled a six-year old, but even so, his small frame had outgrown the wheelchair. James had been reared by his grandparents and had never been to school. His mother had to move to Phoenix to find work and could not take James.

Neither of James' grandparents had any formal schooling, but were considered somewhat better off than most families in their community, since they had some livestock and the grandfather specialized in several curing ceremonies.

During the admission interview, the grandparents explained their reason for wanting to enroll James into the program -- they were getting older and felt he should become more independent. They thought James should learn to walk, so they wanted him to get physical therapy. "We want him to learn to walk, so he can do things for himself, if something should happen to us," remarked James' grandmother.

At home on the reservation, James' grandparents live about 14 miles from the nearest trading post, on a primitive dirt road. The trading post, where they shop, provides their central contact with the rest of the world, and they pick up mail there at least twice a month. James' older aunts and uncles, all living in towns off the reservation, come home on weekends and help haul water and wood for them. The main source of income is livestock, mostly lambs, which are sold to the trader in the Spring to clear debts accumulated during the winter months. Sometimes, the income is supplemented by the selling of rugs which the grandmother weaves and/or money earned by the grandfather as a medicine man.

Clinically, James' medical and social history indicated his diagnosis as cerebral palsy with unknown etiology. The social history revealed that the boy was born in Texas where his parents were relocated by the federal Bureau of Indian Affairs for job-training. Around the age of two, James fell down the stairs in the family's two-story apartment, and was hospitalized, unconscious, for three days. One physician attributed the brain damage to the fall, but James' grandfather seems to think the accident was provoked by witchcraft.

After James had been in the residential program for almost a year, his grandparents came to remove him, saying there were severe financial problems at home and they needed the boy's small social security disability income to help out. This is something that also happened in the past, but as long as James remained in the residential center, the money went to the center to offset the cost of his care and training -- mandated by the funding sources to the center. This situation is not unique. Many other handicapped Navajo individuals are often the only ones in the family with a stable source of income and, therefore, their income is important to the survival of the family as a whole. The dilemma this creates for the family, the disabled, and the programs is a trying one.

Obviously, for sundry reasons, many families of severely disabled children want to keep those children at home, but this is not always possible. When a disabled child is ready to return home, there frequently are barriers. A disabled child who has been taught some independent living skills in the residential centers may regress, since the home environment is not the same as the training centers -- for example -- no running water, electricity nor a floor on which to maneuver a wheelchair or orthopedic braces. Thus, the problems are numerous, both in terms of economics and culture.

One becomes keenly aware of the cultural ramifications for the disabled Navajo children when one realizes that they, like their "normal" peers, must learn to survive in the bi-cultural world of Navajo and Anglo. Because of their more traditional orientation, most parents in this study group looked to the special programs to provide this



type of training/education for their children. Most such existing programs attempt to meet this need by developing bi-cultural, bi-lingual curricula. For example, a traditional Navajo dwelling (a hogan) is evident at almost every program site so children can spend time practicing techniques which will prepare them to function in both kinds of settings. This is easier for the higher functioning students than those who are more severely disabled; children with learning disabilities, for the most part, have fewer difficulties in this area since they live at home and function well there.

The disability's impact on the two groups of mothers in this study was varied, as was expected. In response to the question of how they felt upon first learning of the child's disability, those mothers whose children were disabled by meningitis recalled some reactions of helplessness and confusion during acute stages of the illness. As to the recognition of the residual effects of the infection, most mothers' reactions were less dramatic than expected, since the disabilities were noted gradually. Similarly, mothers of children with learning disabilities could recall few outstanding reactions; they, too, were informed gradually and often with little fanfare.

In contrast, a few of the more educated parents (high-school and college) voiced some anger when they were informed about their child's learning disabilities. Most of the anger was aimed at what mothers viewed as poor quality teaching, and they were convinced that the child's disability could be corrected with proper instruction under qualified teachers. This reaction differs somewhat from the less educated mothers (less than eighth grade), who welcomed the special attention and education for the children and felt that schools were taking appropriate action. Some feelings expressed were: "I don't have any education myself, so I think it is good," and "I don't have anything to offer my child so I hope the schools will help my child."

The parents, for the most part, were not involved in the education of their children. Most felt that allowing children to go to school has been the only demand made, and that this was also the way their own parents felt. Obviously, many such attitudes are tied to the historical

paternalistic actions of the federal Government, which — at first — practically stole children to enroll them in school, not allowing parents to visit nor allowing the children to go home. Since more Indian communities are operating their own schools, this attitude hopefully will change. Parents could then see the value of involvement in their children's education.

In general, most mothers of children with learning disabilities viewed the problems as common and temporary, as something that children "eventually outgrow" and, when viewed in this perspective, there was no need for alarm. More importantly, the child's disability did not pose a problem in the home. "After all," one mother said, "the child functions normally at home."

There was considerable confusion over what mothers viewed as a temporary learning difficulty as opposed to what professionals refer to as a more serious chronic learning disability. A learning disability, as defined by law, is a disorder which affects one or more of the basic psychological processes important in understanding or in using language, spoken or written, and a disorder which may manifest itself in inability to listen, think, speak, write, spell and do mathematical calculations (Public Law, 91-517:4).

Learning disabilities include conditions which result from perceptual handicaps, brain damage, minimal brain dysfunctions, dyslexia and developmental aphasia. The federal laws also make it explicit that these categories do not include other learning disabilities which can be linked to blindness, deafness, mental retardation, emotional disorders, environmental disadvantages and motor handicaps (Public Law, 91-517).

In this respect, the majority of the 15 Navajo children in this study identified as learning disabled had medical histories of Down's Syndrome, microcephelia, prematurity and stressful birth histories — prolonged labor and/or other difficult deliveries.

Because their disabilities were not apparent but were a source of problems in school, not at home, most children with learning disabilities were not treated nor perceived as

being disabled by their families, especially the mothers. The daily routines of these children were also quite "normal"; they lived at home, attended local public schools or attended federal boarding school on the reservation. The following example illustrates how learning disabilities became apparent to parents.

Mollie, a mother, aged 33, with four children, recalls when she first learned that her son, Tommy, aged 8, was going to be transferred from the regular classroom to a special education classroom.

Tommy came home with a note from his teacher saying that he was having problems with reading and math. . . They were going to place him in a classroom where he was going to get some extra help. I didn't think anything of it until about a month later when he came home crying.

He had been teased by the children at school and on the bus. "They called me 'M.R.' (mentally retarded)," he said. I got angry, but didn't do anything. This happened a few times, but one day, he came back with a bloody shirt; he had been in a fight. I took off from work the next day and drove to his school.

I saw the principal, who referred me to the teacher. She, in turn, referred me to the special education teacher. . . then I finally found out what the school meant by 'special help.'

I was told that handicapped children do get a lot of teasing and that it happens to many of the children. I was so angry. . . with the way I was treated, the way my child was being forced to be handicapped. I left the school. . . I wanted to take Tommy out of that school, but I never did. There was no other place for him. My son is not handicapped; he is just having a little difficulty learning. . . He'll outgrow it.

During another interview with Mollie, it was learned that Tommy was born two months premature as a result of an automobile accident; Mollie attributes his "temporary learning problems" to his premature birth. She did not think, however, that Tommy sustained any permanent brain

damage as implied by school officials. Mollie kept saying that Tommy's difficulties in school were due to the "lousy" teachers he had. She stated:

This is his second school. He went to Headstart and then we enrolled him here. He never had any problems at home even though he was born prematurely. He likes to learn. He built a kite last year all by himself. He likes to get stubborn sometimes. . . maybe that is why the school put him in with the handicapped kids.

Mollie had one year of college and Tommy's father attended college part-time; their income placed them in the upper-middle income group of the 30 parents interviewed. Mollie was raised by an Anglo family in Utah; she feels, therefore, she has had less exposure to the Navajo way of life than her husband who was raised in a Navajo foster home. After Tommy, their first child, was born, Mollie and her husband decided to stay in Arizona to live near relatives, in a boarding-school housing unit where Mollie works. At Mollie's insistence, the children were taught only English and raised non-traditionally. Mollie said they also agreed to encourage their children to go on to college.

Two other families in the study group had similar educational backgrounds and wanted their children to excel in school, so they emphasized an Anglo lifestyle and English language in the home. These three families denied anything was wrong with their children. They expressed strong dislike for having their children singled out as "handicapped", although they did not object to the assignment of their children to special education classes. One of these mothers said she was convinced her daughter was conveniently being selected by the teachers because she was not quiet and obedient as were other Navajo children in class.

In contrast, parents who had little or no schooling were more accepting of the school's attempts to help their children. Clara, a 40 year old mother who had never been to school, commented:

The teachers told me Teddy needs to be in that school. They want to help him learn. I am glad they are good to him. If he has an education, it will support him. .

That's what I want for all my children and grandchildren. . . I tell him to do what the teachers say.

Mothers with limited formal education also perceived school officials as the ultimate and appropriate decision-makers regarding their children's educational program. This concept conflicts with the intent of the Public Law which emphasizes parental involvement, but, in the majority of cases, the families said most decisions were made without their consultation. Once the schools notify parents by mail of their action, few parents want to question the decision, afraid that, if they express any opposition, it would mark them as uncooperative parents and perhaps jeopardize their child's program. Many parents also stated they were not qualified to question the decisions and/or recommendations made by school officials.

While many parents were uncomfortable in questioning school decisions, some were more willing to complain if other children bothered their children at school -- a complaint which surfaced in many of the interviews. For example, Ruth, one of the mothers in the study, told how she reluctantly allowed her son, Paul, to return to school after she had removed him to keep other children from taunting him.

(In Navajo) He used to go to \_\_\_\_\_ Boarding School. The children made fun of his speech and were rude to him. He didn't want to go to school because of that. I don't like to have my child suffer like that. I didn't make him go back to school until last year. The people from this public school wanted him to go back to school. They said they would make sure he was not picked on by other children. I think they leave him alone now. He doesn't tell me about it.

Few families of the learning disabled sought assistance outside the school system to help their children. If so, it was usually for some related health problem, as in the case of Leta, who was in special education. Rena, her mother, said Leta always had difficulties since birth -- allergies and accident-prone -- and that she had been told her child's disability probably resulted from a complicated delivery. Rena's sister elaborated by saying that oxygen supply to

the baby's brain was cut off because of the umbilical cord around the baby's neck. The neurological damage also affected Leta's eyesight, so that thick lenses were necessary. The heavy weight would constantly slide the glasses down to the tip of Leta's nose, so the family tried to save enough money to buy her new glasses with plastic lenses.

Rena said she had been told by one physician that there was a chance Leta would outgrow her visual disability. Rena, somehow, interpreted this to mean that the child would outgrow her other disabilities. This expectation, Rena remarked, keeps her optimistic, even when other professionals state that such prognosis is impossible. She recalled her conversation with the physician who gave her such hopes:

I really believed it when he told me that. . .I had a heart problem when I was small and that's what they said so I just thought it was the same thing. . .but now they say that Leta will never be 'normal.' They say that she is retarded and will not be able to do all the things that other 'normal' children will get to do. I still have a hard time accepting that — I think that if I can get her into a special school where there are real experienced and professional teachers. . .she will be able to learn.

Rena's belief that Leta will outgrow her disability is important to her since she has one other child whom she thinks might also be disabled. During the last interview, Rena said she had not had the youngest child tested for fear the doctors would confirm the suspicion. Rena is a single parent; her husband was killed in an automobile accident a day after her second child was born. She works presently as a teacher's aide and lives with her parents in a low-cost tribal housing unit near the school. Rena's father is active in the Native American Church and has occasionally sponsored special prayer meetings for his granddaughter. He commented:

People don't believe that my granddaughter is handicapped. They don't realize she has problems, so when I pray at the prayer meetings. . .I ask for help. I have sponsored prayer meetings for my grandchildren myself. This seems to help them. . .and us, too.

This family's use of traditional healers or the Native American Church was unique; most parents of these children with learning disabilities did not seek traditional healers or other similar resources. If there was mention of a special ceremony or Sing for the children, it was usually a Blessing Way ceremony for all the children in the family, not the disabled child in particular.

Since most parents of the learning disabled view the child's problem as being best handled in the Anglo schools, and since they are rarely called upon to help, they do not feel there is much more they can do. An exception was one mother who stated she bought some books and tapes advertised to help improve reading and comprehension. She worked part-time as an aide in a Headstart program, so had access to information on special books and techniques to help children learn.

As stated before, since most mothers did not perceive the child's learning disabilities as meaning "functionally disabled", there seemed no need to do things differently with this child at home. Similarly, the child's disability had little effect on the family, or on the parental role while the child was small. It is quite possible that, in some instances, as the child matures, the situation may change. As more parents become socialized by the special education program into new parental roles while the child remains in school, then later, perhaps, when the child learns a trade or goes further in school, other changes may occur. For now, however, education -- including the education of the learning disabled -- is seen as the function of Anglo institutions.

In contrast, the mothers of children severely disabled by meningitis were more involved with their children's disabilities. Because such handicaps are visible and attributable to illness, the parental concerns focus on health. Here, the parental role in dealing with family illness comes naturally during the acute stages. For example, most of the mothers sought medical help for their children and wanted to help nurse them back to health from the meningitis. After the crisis subsided, however, most of the mothers were unprepared for the residual effects of the infection. They were not warned by physicians.

One of the Navajo mothers, Desbah, recalled what took place with her son, Raymond:

(In Navajo) They [the medical people] never told us anything. I was worried about him when he turned three and he was not walking yet, so I took him to the clinic. The nurse looked up his record and said that he had an infection which made him that way. He was going to be slow in learning things. That was all she said, like it was nothing. I was very upset and I wanted to know if there was anything I could do. My husband suggested going to a private doctor — so I did. He was the one who explained what happened and where I should go to get some help.

When Raymond got around five years old he started having seizures. The first time he did, I was in the grocery store with him. I thought he was dying. I had never seen anything like that. We took Raymond up to the clinic. I'll never forget it. . .the doctor who saw him just acted as if it was no big deal. He made me feel like a fool for rushing him to the clinic. He gave me some pills for Raymond. At first, I guess, the pills were too strong; they used to make him so sleepy he would just sleep most of the day. It was not until last year they did another examination and the doctor said that they had given him too much medicine. It seems like no one cares or takes the time to explain things to you. I think the doctors think we're just a bunch of dumb Indians.

Desbah shared her experiences and frustrations over a period of four lengthy interviews. Both she and her husband, Robert, have less than an eighth-grade education and live on their combined annual income of \$12,000. Their oldest child and only son, Raymond, is disabled; they have two other children, Becky and Lisa aged four and six, who are both healthy.

Desbah and her family live in a two-bedroom trailer near Farmington, New Mexico. Desbah's mother lives a few yards away in a small three-room house built for her by the tribe. A hogan, nestled between the trailer and house, is used for storage and, periodically, for healing ceremonies. Raymond has had a number of Navajo cere-



monies in the hogan; one ceremony to prevent seizures, and another ceremony performed to help him regain his appetite.

Desbah related:

(In Navajo) Raymond had lost about ten pounds and it is hard to get him to eat anything. The doctors gave him some medicine to make him hungry — but he would just throw it up. My mother got a medicine man to help him. Now he eats like he used to. He needs to put on some weight so his clothes won't hang on him so.

As can be seen, mothers like Desbah were extremely interested in their children's disabilities and eager to explore various alternatives for help. Many sought aid from medicine men, but were also willing to try new modalities, such as Anglo faith-healing. In some instances, the family went outside the reservation to Pueblo healers and/or other tribal healers; however, most families sought help from Navajo medicine men and other Navajo practitioners, such as those of the Native American Church. It was interesting that grandparents played a major role in getting mothers to seek help from medicine men. Some of the mothers said they hesitated because they were not familiar enough with the proper preparation and/or assistance to the patient, and so relied on their mothers or grandmothers to assist. Some of the ceremonies recommended were new to them, also.

In many instances, mothers of children disabled by meningitis resorted to comfortable/acceptable sociocultural explanations of the cause of the child's disability. Three of the mothers thought the handicap was due to witchcraft in cases of jealousy; two mothers mentioned breaking tribal prenatal taboos; another three thought it was because of marriage to a clan relative; and one mother blamed herself for not wanting another child. Some of these perceptions held by the mothers were later confirmed by the Navajo diagnosticians. As would be expected, numerous causes were identified; numerous Navajo ceremonies were recommended to the families.

Because most of the sociocultural explanations address the question of why the disability occurred, there was little

conflict between the Navajo diagnostician's recommended intervention and the Anglo physician's explanation. The physician, in this case, addresses the needs of the child, while the medicine man's intervention is directed more to the needs of the parents and families. This is not to say there was unquestioning acceptance of all medical explanations; prognosis, for example, was not always accepted. Some of the mothers' disagreements on prognosis was largely based on the view that the child was "normal" once and, therefore, if appropriate interventions could be found, there was a chance the child could be "normal" again.

This perception may be seen as being unrealistic and, perhaps, a form of denial, but the view is grounded in Navajo sociocultural perspectives and experiences. The Navajo sociocultural explanation of disabilities among children fall primarily into two main areas: (1) congenital abnormalities present at birth are usually linked to possible prenatal neglect, or abuse of tribal prenatal laws; (2) conditions which occur after birth during early childhood, are often seen as evidence of harm directed at the family by inflicting witchcraft on the most vulnerable family member.

The first explanation places the responsibility of the child's condition on the family or parents, especially the mother. Thus, the appropriate intervention would be to have the child's mother undergo the prescribed Navajo ceremonies, so that she and/or the family is relieved of self-blame. This, as a long-term therapeutic intervention, is important, since it allows the parents to resolve their own guilt and then address the needs of the child.

In regard to treating the disabled child, the traditional Navajo approach of healing ceremonies is less clear. The difficulty arises from the fact that the damage is already done; furthermore, the child is an innocent victim who did not actually bring the disabling condition on him/herself. In many instances, Navajo families will seek help from the medicine men to address only one aspect of the child's handicap; i.e., to decrease the frequency of seizures. In general, Navajo medicine men and diagnosticians agree that children with moderate or severe forms of disabilities are difficult to treat because so many aspects are involved, and

children — unlike adults — do not always have the mental ability to engage in self-healing which is a vital part of the Navajo healing system. Several medicine men also said that children with moderate or severe disabilities could not undergo the strenuous physical demands of some ceremonies, such as repeating long prayers or sitting up all night.

The important aspect of the Navajo healing system is that, if one curing ceremony is not successful, there is always the possibility the ritual was not performed correctly or that additional ceremonies are needed. In other words, there is always hope, so families do not become easily discouraged if all does not go well. Thus, it is logical to expect many families to continue to hope that their children's prognoses will better.

In addition to the sociocultural orientation, there is another factor which colors the perception of these Navajo mothers — that of experience. For many of these mothers, dealing with a disabled child in the home is a new experience, so they have not been locked into some of the typical stereotypes about disabilities; they are not reading books on the subject, nor are they involved in parent organizations which advocate certain programs and/or rights of the disabled population.

Dealing with disability is also a relatively new experience for other people on the reservation. Many elders, for example, said they had not seen any children or adults with the types or severity of handicaps as is now found in the residential programs. One explanation for this, at least in retrospect, may be related to the significantly high infant mortality rates a few years ago. Also, until the introduction of antibiotics, many of the infectious diseases such as meningitis were usually fatal, thereby leaving few children to survive with chronic disabilities. Another factor is that some of those who did survive after severe disabling illnesses were permanently institutionalized in off-reservation facilities.

Despite the problems posed by economic and cultural factors, however, the new experience of having a disabled child did not create major barriers for the Navajo families.

For example, the extended family and kin provided important support and cooperation to the families when in need, and thereby shared parental responsibilities. Even where the child had a single parent, the child-rearing and child-care were commonly shared by extended family members, such as grandmothers, aunts, and clan relatives.

In Navajo culture, a child has multiple "mothers," any one of whom can serve as surrogate mother. Grandmothers are called "mother-elders;" aunts, "little mothers," and anyone who is not blood kin, but is of the same clan as one's mother is referred to as "mother." Aunts and grandmothers, however, are the most common surrogate mothers. Three of the children in the study, in fact, were reared primarily by grandmothers, often to allow the child's mother to maintain employment outside the home. In one case, the child remained with the grandparents to whom he was very attached, when his mother remarried and had to move.

As can be seen, the availability of multiple surrogate mothers helped ease some of the parenting responsibilities by partially decreasing a stressful situation. Because of the strength of the Navajo cultural pattern, the anticipated stress on the parenting role was less evident, even in circumstances with the more severely disabled children. The buffer, here, appears to be that the disability was perceived as illness-related, and therefore other kin and relatives came to the aid of the families when called upon. More importantly, as these moderately to severely disabled children reached school age, the families were able to place them in programs on the reservation under the care of professionally trained Navajo experts. The placement, viewed as training and educational opportunity for the disabled child, also alleviated some of the potential stress and demands on the parents.

It is important to mention here that, although many parents were glad they enrolled their children in the programs, they were not always anxious to institutionalize their disabled children. Many continued to say that if there were resources nearer, they would prefer to keep their children at home.

As to the history of early child-rearing practices, most of these mothers of moderate to severely disabled children

said they did not treat the child differently from siblings, except in situations where the handicapping condition limited the child's capability. For example, 56% of the disabled children had their first laugh celebrated; 50% had Indian names; 43% used traditional cradleboards; and 40% had their umbilical cords buried in accordance with tribal custom. In rating cultural abilities of the children, mothers indicated that 83% of the disabled children spoke Navajo, and 63% could name their mother's clan.

In summary, the introduction of a disabled child into the Navajo family did not greatly disrupt the family's lifestyle and/or parental roles. Siblings were not displaced by the increased attention paid to the needs of the disabled child while at home. Where the disabling condition was viewed as resulting from illness, relatives offered assistance and surrogate mothers helped with child-care. The common acceptance of multiple mothering in the Navajo culture also helped eliminate possible problems with strangers in the institutional settings on the reservation who assumed parental responsibilities. Many of the staff members of these centers, such as the child-care workers, were clan relatives and were viewed as appropriate in fulfilling surrogate parenting roles.

In conclusion, despite the fact that the parenting of a disabled child is a new experience for most of these Navajo families, they have managed well. Where mothers were unable to find answers, they felt it was natural to resort to explanations and concepts which are part of the Navajo culture; as a result, the Navajo social structures and cultural patterns helped ease the parenting role in dealing with the unknown. Unfortunately, this cultural value and pattern will probably become less common as the acculturation process continues. The increasing numbers of nuclear families moving from the reservation to live in cities and towns point to this trend. This, of course, affects the concept of multiple mothering and the helpful network of kin. The shift from nuclear family living patterns means the bulk of parenting responsibilities will become assigned only to parents, which usually means the mother, alone.

## NOTES

<sup>1</sup> Material for this paper was drawn from the author's unpublished Ph.D. dissertation, 1980.

<sup>2</sup> Names used throughout the paper are pseudonyms.

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